

## **IDS Working Paper 224**

### **MMR “choices” in Brighton: understanding public engagement with vaccination science and delivery**

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## **Summary**

In the context of the high-profile controversy that has unfolded in the UK around the combined measles, mumps and rubella (MMR) vaccine and its possible adverse effects, this paper addresses how parents in Brighton are thinking about MMR for their own children. Research focusing on parents' engagement with MMR has been dominated by analysis of the proximate influences on their choices, and in particular scientific and media information, guiding policy to focus on information and education. The ethnographic work in Brighton reported in this paper, to be complemented by survey work, begins to question the validity of such reasoning by showing how wider personal and social issues shape parents' immunisation actions. Extended parental narratives show how parents' practices around MMR are shaped by their personal histories, by birth experiences and related feelings of control, by family health histories, by their readings of their child's health and particular strengths and vulnerabilities, by particular engagements with health services, by processes of confidence-building and undermining, and by friendships and conversations with others, which are themselves shaped by wider social differences and transformations. "MMR talk" has become a social phenomenon. Many see vaccination as a personal decision which must respond to the particularities of a child's immune system. These perspectives both challenge key tenets of public health policy, and suggest ways in which people's engagements with MMR reflect wider changes in their relations with science and the state.



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## 1 Introduction and aims

The number of parents presenting their children for the combined measles, mumps and rubella (MMR) vaccination has declined significantly during the last five years and in some areas, continues to do so. Publics, policy-makers and academics alike see the MMR issue as an increasingly important and high profile example of emergent problems in public trust in and engagement with science, and in science communication.

Research focusing on parents' engagement with MMR has been dominated by analysis of the proximate influences on their choices, and in particular scientific and media information. This paper questions the validity of such reasoning (and policy premised on it), by showing how wider personal and social issues shape parents' immunisation actions. It moves from a vocabulary of how information guides decisions, to the social processes shaping immunisation practices.

This paper is based primarily on narrative interviews with mothers. These indicate how their immunisation practices need to be understood in relation to their more personal histories (birth experiences, engagements with health services, friendships, readings of their child's health, family histories etc) which are themselves shaped by wider social differences and transformations. This helps us understand why MMR has sometimes been understood as a class issue, but also helps us move beyond this in recognising the importance of other social experiences which cross-cut "class" distinctions. This also helps us understand the emergence of the MMR controversy as part of wider changes in people's relationships with science and the state, rather than as a temporary aberration which will fade away.

Our aim in this paper is not to participate in the ongoing scientific debate over MMR, or to take sides in it. Rather, we explore, amidst this scientific debate and publicity around it, how ordinary mothers in Brighton are thinking and deciding about MMR for their infants. In revealing their perspectives, the paper highlights certain weaknesses in the existing analyses of parental attitudes and beliefs that have guided policy to focus on information and education.

Immunisation action is certainly influenced by information. However, our findings suggest that how people interpret this information depends on both wider social processes and the particularities of parent's situations. Furthermore, whether people's interpretations actually reflect or correlate with what they do depends on further issues, including their personal feelings of confidence, and their positions in relation to structures of authority.

Narratives show that engagement with MMR is influenced by experiences over a much longer period than is currently appreciated. This would help account for both the sense of disempowerment, anger and misrepresentation that many parents express, and for limitations in the capacity of public health education strongly to influence parent's decisions.

This paper is a preliminary report deriving from anthropological research in the city of Brighton and Hove, East Sussex. It is based on in-depth interviews and ethnographic studies which are ongoing, and which *make no claims to cover a statistically representative sample of parents*. This work will, however, be complemented by a postal questionnaire survey to probe and quantify the wider significance of the

emergent ethnographic themes across a random sample of parents in the city. An earlier version of this paper, and the survey plans, were read and discussed by a Stakeholder Advisory panel comprising key representatives from policy-making, health care professionals' and parents' organisations involved in the MMR debate in the UK, and by local health care professionals. This study of MMR in Brighton is itself part of a broader research project on 'Childhood Vaccination: Science and public engagement in international perspective' funded by the Science in Society Research Programme of the British Economic and Social Research Council (ESRC).

## **2 Contextualising public engagement with MMR: issues and methodological approaches**

Certain parents and parental groups came to attribute autism-like symptoms in their children to the MMR vaccination in the mid 1990s.<sup>1</sup> Arguably, their views gained credence from clinical studies of a small number of such children (Wakefield *et al.* 1997, 1998; Uhlmann *et al.* 2002). These followed research suggesting that the measles virus plays a role in the development of inflammatory bowel disease (Wakefield *et al.* 1993; Ekbom *et al.* 1994; Thompson *et al.* 1995). This association has in turn been contested (e.g. Seagroatt and Goldacre 2003; Ghosh *et al.* 2001). Numerous studies have considered the incidence of autism (and in some cases, the related bowel disease identified in Wakefield's study) in relation to MMR among larger populations, and do not show an association (e.g. Taylor *et al.* 1999, DeWilde *et al.* 2001; Fombonne 2001; see Miller 2002 and Jefferson *et al.* 2003 for reviews). As medical, social and media debate around this controversy has unfolded, parental engagement with the MMR vaccination has altered. Despite assurances in the scientific literature and by the British Department of Health (DH) on the safety of MMR, and despite information campaigns aimed at parents, uptake continues to decline in many areas. According to the latest HPA (Health Protection Agency) statistics for England, vaccine uptake for children reaching 2 years of age between July and September of 2003 currently stands at 79.8 per cent (HPA 2004). NHS Immunisation statistics for England for the period 2002–03 revealed a figure of 82 per cent (NHS *Immun. Stats. Bulletin* 2003/16) a drop of 2 per cent compared to the previous year (see also PHLS 2003 for analysis of the COVER programme, Oct–Dec 2002). As some parents opted for single vaccinations, a second debate has emerged concerning access to these and whether they should be made available through the NHS.

A variety of literatures offer different perspectives on the ways that parents have reacted to this debate. Policy-makers have asked why it is that publics appear not to appreciate that there is no valid scientific evidence of a link between MMR and autism. A predominant view, especially in health policy circles, is that the public misunderstand the science involved, and thus misperceive the supposed autism risk (e.g. Elliman and Bedford 2001). This idea of a "deficit" in public understanding, to be filled by

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<sup>1</sup> For example an early documented reference to a parent making a connection between MMR and autism in public was in 1993 by a mother in a Danish television programme (Health Education Board for Scotland 2001).



science education, has characterised views of the public over many issues involving science. From this perspective non-vaccination is seen at least in part to reflect misinformation or ignorance which needs to be corrected by the provision of scientific information. This is the cornerstone of the current DH strategy, which provides scientific information catered to both the public and health professionals (Department of Health 2001; NHS 2004).

Other studies focus on the role of pressure groups and the media in “misleading” and “misinforming” publics. Thus, for example, André (2003) has argued that ‘a small group of so-called educated in developed countries’, who constitute an ‘anti vaccination movement’ have been misclassifying health events after vaccination as vaccine reactions. Advocacy groups, that easily interact with media and engage with parental and wider social concerns have a long history in the UK. They articulated with considerable dissent to the smallpox vaccine in the 1880s (Durbach 2000) and to the pertussis vaccine in the 1980s (Baker 2003). Whilst easily dismissed by their critics as “anti-vaccination”, this overlooks the considerable diversity of the concerns that they represent.

Equally, the argument is made that the styles of mass-media coverage, “miscommunicate” and amplify risks to publics. As Cookson (2002) shows, journalistic writing about vaccines in British newspapers increased in the 1990s, with a disproportionate increase in articles about safety issues. “Scare stories” about vaccine risks strongly outnumber those about vaccine benefits. It is argued that public anxiety about MMR has been fueled by (even created by) the “biased” lines adopted by particular newspapers and journalists; the tendency to give equal column inches to each “side” of the debate, so that the public reads what are arguably minority scientific/public positions as a 50:50 split; the highlighting of emotive stories of parents with vaccine-damaged children, and of “David and Goliath” stories of “maverick” scientists against “the establishment” (e.g. Ramsay *et al.* 2002; Hargreaves *et al.* 2002; Science Media Centre 2002). The controversial role of media in its interplay with public engagement with vaccines has been discussed in relation to Pertussis (Baker 2003) as indeed elsewhere in the world (e.g. Leask and Chapman 1998, 2002).

Those who dismiss parent’s concerns with MMR as based on a misunderstanding of science find their confidence in a particular view of what counts as the most convincing “scientific evidence”, namely the population-scale, epidemiological studies that have not shown a link between MMR and autism. The potential links that have been suggested are supported only by clinical findings based on the case histories and bodily processes of individual children. This carries much less weight as evidence, especially given the lack of supporting epidemiological studies. Critics have explored ways that some of these clinical findings are methodologically flawed, or incorrectly interpreted (e.g. Miller 2002), and thus, it is suggested, they are bad science, or not even qualified to count as science.

An alternative reading would see this debate as between different types of scientific inquiry, with different emphases. Thus some parents who have observed changes in their own children, and certain doctors in working with individual patients, find that certain strands of clinical scientific work support

their own experience. They are critical of the epidemiological work which denies the validity of their observations and interpretations. They highlight how population-scale studies which claim to disprove an MMR-autism link, despite their number and “weight” in the published scientific literature, are themselves either methodologically flawed or biased in interpretation (e.g. Thrower 2003) critiques which have also been elaborated by a number of health professionals.<sup>2</sup> Some also argue that while epidemiological studies have been focused on autism in general, their children have a particular MMR- linked disease which, whilst exhibiting autistic like symptoms, is distinct. These perspectives have been developed within localised support groups for the parents of vaccine damaged children and their national alliances (e.g. “Jabs”) sustained not least through internet communication and dedicated websites. These have become focal points for comparative parental experience, forging a “citizen science” that has engaged with similarly-interested clinical scientists in the UK and elsewhere. So, although case-based, personalised stories are the stuff of good journalism and might be construed to amplify misinformation, they can also be seen as resonant with one part of a spectrum of types of scientific inquiry ranging from the individual to population-scale of analysis.

Amongst the various literatures which have emerged around the MMR issue are social science studies that have explored parents’ perspectives and practices around MMR (and immunisation in general). These have considered media and pressure group influence, but in the context of other questions concerning public understanding and practices. They range from studies which consider people’s behaviour to depend on individual “knowledge, attitudes and beliefs”; on economic and class factors; on culture and social experience; on issues of confidence and trust in expert institutions, and on personal and societal reflection on the forms of social control embedded in public health interventions.

Studies addressing the “knowledge, attitudes and beliefs” of parents have focused particularly on perceptions of the benefits and risks of immunisations and sources of information about these. For example, the DH supports regular surveys in random locations across England which probe mothers’ attitudes through interviewer-administered questionnaires. Their latest published survey indicated that 67 per cent of mothers reported that the MMR vaccine was safe or carried only slight risk. Variations over preceding years were understood to be linked to media coverage (Ramsay *et al.* 2002).<sup>3</sup> They concluded that:

... the fall in MMR coverage has been relatively small, mothers’ attitudes to MMR remain positive, and most continue to seek advice on immunisation from health professionals. As the vast majority of

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<sup>2</sup> See, for example:  
[www.mercola.com/2001/feb/7/mmr\\_vaccination.html](http://www.mercola.com/2001/feb/7/mmr_vaccination.html);  
<http://libnt2.lib.tcu.edu/staff/lruede/Fin2.html>;  
[www.theecologist.org/archive\\_article.html?article=284&category=61](http://www.theecologist.org/archive_article.html?article=284&category=61)

<sup>3</sup> The ‘Knowledge, Attitudes and Beliefs’ framework, sometimes referred to as the ‘Health Beliefs Model’ has guided many studies of parental engagement with immunisation in many countries (e.g. See Harding 1984; Bond and Nolan 1998).

mothers are willing to have future children fully immunised, we believe that health professionals should be able to use the available scientific evidence to help to maintain MMR coverage.

(Ramsay *et al.* 2002: 912)

Pareek and Pattinson (2000), also conducted a (postal) survey focusing on attitudes, beliefs and media, with similar results, and affirmed the need for further educational campaigns emphasising the safety and efficacy of MMR. Whilst focusing on knowledge and attitudes, both these studies also found that attitudes to MMR are linked to social variables such as age, education, marital status, ethnicity, and in particular to class, associating (at least early) concern over MMR with those from higher socio-economic grades; this was, for instance, a finding of the DH tracking surveys. Other studies of immunisation and indeed the views of some health professionals associate non compliance either with an educated middle class, or with a small minority of people that would never be reached either by immunisation or other health services (e.g. Egan *et al.* 1994).

Other studies show the need to go beyond issues of individual beliefs and social status when explaining immunisation behaviour, to consider how culture, and social and political processes, shape parents' dilemmas and eventual practices. For example, a set of studies in different countries coordinated by Streefland *et al.* (1999) concluded that vaccination acceptance turns on (a) how vaccination engages with local knowledge, aetiologies and perceptions of disease, and (b) specific socio-cultural contexts and experiences of interaction between people and health care providers. He characterised these together as 'local vaccination cultures' (Ibid: 1707). In this vein, several studies have associated vaccination refusal with particular social groups having "alternative" lifestyles and philosophical outlooks around issues of health and environment, and critical ways of relating to "mainstream" medicine (e.g. Rogers and Pilgrim 1995) – although other "vaccination cultures" could be linked with vaccination acceptance.

Whilst these works suggest the importance of considering the varied ways in which people interpret medical information within their own cultural and conceptual frames of understanding, they also draw attention to political dimensions to cultural experience, and begin to raise questions about people's confidence and trust in engaging with health institutions. Academic and popular discourse alike suggests that people are now less willing to place unquestioning trust in "expert" institutions. In medicine (Williams and Calnan 1996; Gabe *et al.* 1994) as around other issues involving science (e.g. Fischer 2000; Irwin and Wynne 1996) many people are increasingly inclined to treat "official" views with doubt and skepticism, seeing them as only one possible viewpoint among many, including popular knowledge. Equally, it is argued that people are more inclined to question the institutional positions, motivations, funding and wider political agendas of those giving scientific or public health advice. Aspects of these trust issues have surfaced in relation to vaccines and MMR. Meszaros *et al.* (1996), for example, found skepticism over the reliability of vaccine information to be a significant factor in parents' refusal of Pertussis vaccination. Some parents' skepticism over claims that MMR is safe have been linked to the perception the GPs are "paid to immunise", or that scientific research claiming MMR safety is biased by its funding by interested

pharmaceutical companies (Evans *et al.* 2001). Notably, however, some evidence suggests that amidst a generalised decline in public trust in “expert” institutions, doctors are trusted more than any other group.<sup>4</sup>

Questions of trust themselves raise further issues about the relationship between immunisation and broader processes of social and political control. Some analysts draw out how medicine and public health interventions are part of a system of techniques and technologies of power concerned with the moral regulation and “normalisation” of the population through actions on the body (Turner 1987; Foucault 1979) – and vaccination regimes with their aspirations to universal reach and their “social good” element are a case in point. Yet it is also argued that people and institutions are becoming more aware of and critical of such processes of control (Williams and Calnan 1996); a critique visible in some strands of anti-vaccination literature (Scheibner 1993; McTaggart 2000; Coulter 1990). That this may not be so novel is indicated, however, by Durbach (2000) who documents working class dissent from mandatory smallpox vaccination in the 1880s which understood it as an intrusion of state public health policy into personal life, and a symbol of class oppression (see also Baker 2003). Despite this deeper history, sociologists now make the strong argument that tendencies to control are inevitably undermined as the risks thrown up by modern technologies become more visible and pervasive, and apparently beyond the capacity of established public institutions to manage or contain (Beck 1992). Questions thus arise about whether the MMR controversy is part of a more general societal phenomenon of this kind.

These broader considerations around culture, social process and the changing relationships between publics and expert institutions suggest some inadequacies in explaining parents’ views of MMR in narrow terms of risk perception. They raise new questions, whose answers may help explain why attempts to alter behaviour through influencing risk perceptions have foundered. It becomes important first, to understand the conceptual terms in which parents think about MMR “risk”, and to recognise that their cultural and experiential perspectives may lead them to think about the issue in different terms. Second, where people are aware of disagreements amongst experts and of the fallibility of expert institutions, they may consider the issue not as one of risk – where there are calculable probabilities among known outcomes – but as an issue of scientific uncertainty or even ignorance, where there may yet be more “unknowns” to emerge from vaccine effects. Third, people may lack trust in the institutions which provide such information.

Studies which enable parental concerns to emerge spontaneously (rather than depending on preset questionnaires) suggest the relevance of all these questions of beliefs, class, culture, political experience and trust. This was the case in Evans *et al.*’s (2001) qualitative study of parents’ engagement with MMR in Bristol, for example, and its findings and conclusions serve as a useful marker in the following discussion as we come to explain our own study’s approach. Based on focus group discussions with immunisers and non-immunisers, Evans *et al.*’s study questions the conclusions and policy emphases on education of both Ramsay *et al.* (2002) and Pareek and Pattinson (2000). Whilst they identified beliefs about the risks and benefits of MMR compared with contracting the diseases, and information from the media and other

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<sup>4</sup> ‘Doctors win overwhelming vote of confidence from public’, MRI opinion poll conducted for the British Medical Association, March 2001. [www.mori.com/polls/2001/bma2001.shtml](http://www.mori.com/polls/2001/bma2001.shtml)

sources about the safety of MMR to be significant, they also found confidence and trust in the advice of health professionals, and views on the importance of individual choice to be significant influences on parents' decisions (Evans *et al.* 2001: 904). In contrast with the other studies, they reveal how *all* parents, even MMR acceptors, found the decision difficult and stressful and how they resented pressure from health professionals to comply. They showed how both MMR immunisers and non-immunisers share many views on the MMR vaccination, and understood and respected each others' decisions, and thus questioned the strong analytical distinction that is usually drawn between them.

Issues that Evans *et al.* (2001) raise can be taken further. First, Evans indicates the absence of peer pressure among parents, and a respect of individual decisions about MMR. This raises interesting questions about how parents relate with each other over this issue and how these attitudes are formed through kinds of interaction with other parents. Second, although non-immunisers appeared to balance perceived risks and benefits, and resented a policy that they perceived as restricting their choice, immunisers generally "chose compliance", rather than making an informed positive decision. This highlights broader questions concerning issues shaping people's ability and confidence to choose. It also questions the assumption that information and education will support informed choice if, in fact, people are choosing to comply for other reasons. Most parents who had by their own account assessed the risks and benefits of MMR, felt that the information available to help them make this decision was insufficient and unreliable and that health professionals were not easily available to support them. This raises further questions about the extent and quality of parents' interactions with different health professionals and information sources in the context of the broader processes shaping their decisions. Third, the majority of non-immunisers found it easier to live with the potential consequences of "natural" process rather than of a definite action (immunisation), which might cause harm. Thus in the face of uncertainty, study parents' immunisation decisions could not involve simple "rational" risk/benefit analysis, but were shaped by personal and cultural perceptions of responsibility. This also raises further questions about people's concepts and perspectives on issues such as disease, immunity, risk and vulnerability in relation to child health. The study indicates the need for immunisation services to 'work with parents' to restore their confidence in MMR immunisation (Ibid 2001: 909), and not simply educate. Although Evans' study suggests the need to appreciate immunisation within a wider social picture, this, and the questions arising, still remain relatively unexamined in the paper.

## **2.1 Ethnographic perspectives**

To explore these questions further requires greater attention to parents' personal experiences, reflections and creativity, within the social processes and relationships in which they are involved. By their nature, the focus groups that Evans used are good at revealing commonly held themes, but are less able to reveal the process of particular mothers' decisions. These studies suggest the need for a research strategy which is, on the one hand, attentive to particular parental biographies, and on the other, to locating this in people's broader social context and experience of authority. To do this, the first phase of our research has combined a focus on (a) parental biography in relation to immunisation practice, (b) participant

observation in locations where the issues are discussed, and (c) interviews with health professionals (and shadowing of their work) in these locations.

This approach enables us to consider how individual parents engage with the issue of vaccination over a period of time, as reflected in their retrospective accounts of how their views and practices have formed – an engagement which need not end in a concretised attitude or belief that would necessarily predict final action (in contrast to Pareek and Pattinson 2000). Indeed as the narratives show, many parents do not know why they ultimately chose. There is often a sense of continuing ambiguity, while the final reasons people give for their actions may be heavily dependent on memory and current events, and may fail to reveal forgotten influences or issues. Nevertheless, people can still reflect on the process they have gone through in thinking and deciding about MMR. In order to engage in dialogue with parents, the final justifications that they give may be less important than an appreciation of their uncertainties and dilemmas in interpreting information in relation to its source, and accumulated experiences of health related institutions.

Viewed in this way, the diversity of parents' narratives follows from the different processes that parents have gone through and not exposure to, or engagement with might be regarded as a variety of “key influences” on a “choice”. Indeed, the concept of “choice” (concretised apparently in immunisation “decision”) starts to look like an increasingly problematic analytical category. The themes that emerge indicate how parents associate their immunisation practices with other areas of their life and experience, which the questionnaire will probe further for their explanatory value.

Through particular parental biographies, one can appreciate how the ways that a parent accesses and interprets immunisation knowledge relates to their life history. When parents do not vaccinate they are not necessarily merely making a statement about their scientific reading, but also to varying degrees about what they regard as valued parenthood, their responsibility to their child, the right of parents to choose, their trust in the medical establishment and their position in their trajectory of interest in the issue, how they place themselves with respect to their friends, and so on. Narratives can also pick up how people present their opinions in relation to how they understand and present themselves socially. Finally, narratives and participant observation can indicate how the context of a research encounter and culturally and locally sensitive ways of presenting information influence what people say. Thus it might also help identify the biases in focus groups and attitudinal surveys.

### **3 Study methods**

In the light of the discussion above, our methods combined:

- (i) Detailed narratives among a diverse group of mothers (details of selection criteria are given below) that permitted them to speak as much around the issue as possible and to reflect what they regarded as being most important.

- (ii) Participant observation and short, informal discussions to consider how people talk about MMR amongst themselves, and to understand further the social and analytical frameworks within which parents consider immunisation practice.

The nature of this kind of interviewing and ethnographic work means that while similar questions may be asked, the context and biographical nature of narratives and informal encounters means that they are not comparable in a truly quantitative manner. The issues raised by ethnographic work can, however, be quantified and this is the intent of the survey.

- (iii) An examination of parents' engagement with MMR in relation to their interactions with "frontline" health professionals. Ramsay *et al.* (2002) and Pareek and Pattinson (2000) suggest that health professionals are key to parents' decisions, while other work that the DH carries out with both parents and health professionals, largely in group discussion settings, suggests that health professionals' attitudes are of key importance. Our approach aimed to focus in greater depth on the interactions between particular health professionals and parents. This allows exploration of the social and political relations underlying categories such as "trust" (e.g. parental fears that non-immunisation or immunisation may lead to problems for which they will be blamed). It also allows exploration of how the attributed personalities of frontline workers, as well as their professional roles, are significant to parents, and of how GPs and Health Visitors (HVs) broker more personal concerns with professional directives. Our research approach has involved not just carrying out extended interviews with eight GPs, three practice nurses and six HVs concerning how they position themselves and interact with parents over the MMR issue, but has also attempted to engage them as research collaborators, enabling their own questions emergent from this brokering to be reflected in the research.

### **3.1 Research sites and ethnographic sample**

Two areas of Brighton were chosen for the ethnographic study. These sites were deliberately identified for their apparent conformity to stereotypes of "deprived" and "middle class" areas – polarities which have been important in media and some policy debate over supposed attitudes to MMR. Nevertheless "deprived" Whitehawk covers some rather better-off pockets, while "middle class" Fiveways/Preston Park is not without poverty.

Many parents in Whitehawk feel themselves unjustifiably stigmatised. Many express satisfaction in living there, because of the greater sense of community and involvement in each others lives, although acknowledging the presence of some people who cause problems. There are many reasons why particular parents would be living in Whitehawk: some are old-time Whitehawk, others have moved due to affordability, while others have been housed there from estates elsewhere. (For a history of the estate and suggestions as to why it has been stigmatised from its origin, see Netley 2002.)

Brighton's Fiveways and Preston Park neighbourhoods are characterised by commuters, families who have moved to the area for its good schools, and Sussex-based professionals including university academics. Stereotypically, they are seen as part of Brighton's *Guardian*-reading "muesli belt".

Having selected these study areas, a focal GP practice in each was identified through (a) compilation of a shortlist of four practices in conjunction with the immunisation coordinator of Brighton and Hove Primary Care Trust, and then (b) interviewing the Practice Manager and contacting a key GP partner of each shortlisted Practice. Selection criteria were (a) serving a significant proportion of the families in the study area, with at least 200 children registered with the Practice; (b) having at least two practising GPs, and (c) interest in the study questions and willingness to collaborate. Following these discussions, it was decided not to use one Practice as it covered too large an area, insufficiently focused on the study community, while one Practice itself declined to participate largely due to pressure of work. The selected Practices were the Whitehawk Surgery in Whitehawk, and The Surgery in Beaconsfield Villas which serves residents of the Preston Park/Fiveways areas. Neither Practice either self-identifies, or is identified by the PCT, as having any particular “take” on MMR. In each Practice, we interviewed all GPs and Practice Nurses. In parallel, we contacted the Health Visitors’ base serving each study area and interviewed all available HVs, going on to carry out follow-up interviews and shadowing of work with three who were interested and willing.

We met parents in a wide variety of different parent-toddler groups during March–May 2003, ranging from groups organised by health professionals and community workers (Groups A and B) to informal drop-in sessions coordinated by the National Childbirth Trust (Group C) and a social-services supported community centre (Group E), to an organised physical activity/music class (Group D). Several of these settings were used as the base for four focus group discussions convened amongst the mothers who happened to be present on a particular day. No advance attempt was made to bring together mothers sharing any particular view. Many short, informal discussions and much participant observation of “MMR talk” amongst parents also took place during our visits to these parent-toddler groups, and during the anthropologists’ presence in the study areas. 48 of these conversations were recorded, and 23 developed into in-depth, narrative interviews of 1–2 hours in length.

To date such interviews have only been with mothers, and further interviews with fathers/involved male carers are planned. This has constrained the scope of this working paper in two main ways: first, in seeing MMR engagement and practices only through mother’s eyes, and second in discussing relations between parents over MMR only from one side. We recorded and transcribed all in-depth interviews and group discussions in full.

The 23 mothers whose narratives form the main evidence base for this paper do not, of course, constitute a random sample. The only selection criterion was mothers’ willingness to be interviewed, either at the time and location of meeting them or at home or another mutually-agreed location after further arrangement. They were contacted at 5 different parent and toddler groups (Groups A-E in Table 3.1) or introduced by one of 6 different people (two health visitors, one doctor, one community worker, one social worker). We spoke to only two mothers (see first line of Table 3.1) who were recommended to us on the basis of their vaccination decision. (One was recommended to us by a doctor as an interesting case



of non-vaccination. The other was suggested to us by a mother who thought we should interview someone who vaccinated despite having an autistic child.) Table 3.1 summarises how these mothers were introduced to us.

**Table 3.1 Mode of introduction of mothers interviewed in-depth**

Mode of introduction	Location	Number of mothers
Personal recommendation on the basis of vaccination decision.	Whitehawk (& Lewes Road)	2
Introduced by health visitor (HV6) during shadowing.	Fiveways	2
Introduced by health visitor (HV1) during shadowing.	Kemptown	1
Introduced by community worker	Whitehawk	1
Introduced by social worker.	Whitehawk	1
Met in Group A	Whitehawk (Manor Farm)	6
Met in Group B	Preston Park	4
Met in Group C	Fiveways	3
Met in Group D	Fiveways	1
Met in focus group at Group E	Whitehawk	2
TOTAL		23

The mothers we interviewed had a variety of social, demographic, educational and occupational backgrounds, although these were in no sense prior categories. They had also made a variety of vaccination decisions for their children, which are summarised in the table below.

**Table 3.2 Vaccination decisions made by interviewed mothers**

Vaccination category	Number
MMR (all children)	7
MMR (all children)/postponed	2
MMR (one or more children), Non Vaccination (one or more children)	2
Single vaccines (all children)/on time	0
Single vaccines (all children)/postponed	2
Postponed DTP/no MMR (Intention to vaccinate)	1
Postponed DTP/Undecided MMR	1
DTP/ no MMR (postponed/undecided)	1
DTP/no MMR (postponed/decided to go ahead)	2
DTP/no MMR (undecided)	1
DTP/no MMR (Intention to have single mumps vaccination)	1
DTP/single measles vaccination	1
DTP/no MMR/waiting for children to decide	1
Non vaccination (all children)	1
TOTAL Mothers.	23
TOTAL (Have had MMR or intention to go ahead).	11
TOTAL Whitehawk residents	11
TOTAL Preston Park/Fiveways residents	12

## **4 Thematic findings and emergent issues**

We have provisionally analysed mother's narratives according to themes that they suggest are relevant in parental engagement with MMR. We now go on to outline these and offer some quotations as illustrative of them. In documenting these fields of relevance, no claims are made for their statistical significance at this stage given the proposed questionnaire which will explore them further.

The themes broadly follow the "biographical process" of coming to a decision:

- Mothers' personal histories: setting the stage for engagement with vaccination.
- Control over birth events
- Becoming a mother with other mothers
- Engaging with health professionals
- Parents' research and thinking about vaccination
- Wider trust in science and government
- Understandings of vaccination and contra-indications
- Final action?

### ***4.1 Mothers' personal histories: setting the stage for engagement with vaccination***

Parents bring to parenthood and the issue of vaccination for MMR a wealth and diversity of previous experience, knowledge and ways of validating and engaging with information. They also have experience and expectations of health professionals, and value and expect particular ways of being treated and informed. Narratives show how these set the stage for MMR engagement.

In getting to grips with MMR many parents draw on the history of vaccination decisions and disease experiences in their own families, including their own childhoods (although this can be frustrated by lack of information), and in others. Some parents have been brought up in families with either a longstanding rejection of all vaccination, while others have a history in which vaccination is very much valued. Most parents, however, have a family history in which vaccination or experience of serious effects of childhood diseases plays a minor role. Despite the small number of complete non-vaccinators, many parents are familiar with children who have been brought up without vaccination with, they perceive, seemingly little ill effect.

My mum thinks that in the past when there was no midwives and health visitors they just got on with it. Mum thought she didn't think it would work for us, she thought if we were ill we would be ill.

(Mother)

Experiences of oneself and others catching childhood diseases with few serious effects, or less frequently, having complications from them, also feed into people's perspectives on vaccination. Some parents in their deliberation of MMR actively pursue such histories, questioning relatives or friends to discover whether they themselves were vaccinated for the diseases concerned.

Parents also draw on other familial, professional, personal, philosophical and travel experiences when they start to engage with vaccination. In particular, the narratives suggest that previous medical experiences or contact with medical professionals (either within or outside the family) influences trust or suspicion of biomedical recommendations to vaccinate. Those mothers who are also health professionals did not all hold unquestioning acceptance of vaccination, but (depending on experience) also narrated their increased awareness of iatrogenic disorders, medical mistakes and possibilities of error. Equally, the narratives show how longstanding sickness or inherited conditions lead some parents to gain more insight into the practicalities, politics and pitfalls of healthcare than the theories supporting medical treatment.

Some parents have political and philosophical attitudes that make them suspicious or put off by what they experience as heavy-handed or patronising denials of their ability to choose for themselves. Some have become suspicious of the drug companies' involvement in vaccination programmes. Inversely others come from families with a history of compliance born of economic need that makes them ill prepared either to research or to feel confident to criticise. Individual parents may acknowledge particular personality quirks or phobias that make them apprehensive of biomedical intervention, however mild it may be.

Only four of the 23 mothers expressed that they always knew their children would be vaccinated and that they did not have any problems with the MMR. Notably, these four all also made implicit and explicit distinctions between themselves and other mothers on the basis of their personal histories.

Only one mother linked her perspective to a claimed scientific knowledge of the issue. She had a PhD in a biological science and both her parents had worked in the health service (her father worked as medical laboratory scientist in pathology labs). This mother had also been the subject of measles vaccine research in the 70s, had extensive work experience of communicating scientific research to funding bodies, and had met someone who had Polio in the 1950s. This constellation of work and life experience must go some way to contextualising the fact that hers was the only explanation of a mother who claimed scientific knowledge (albeit guarded) of the issue and demonstrated little worry with the MMR.

The other three mothers narratives highlight a range of issues which also need to be understood in relation to their own backgrounds and experiences in other domains. These include (among others) (a) a trust of professionalism, (b) a suspicion of the media (c) an acknowledged ignorance of the issues that they see other mothers and doctors valuing (d) an acceptance of the MMR/autism connection as one risk among many (captured in the statement "There's a fine line to tread. It's what you want for your children, whether you can cope with a bit of Autism or blind and deafness, it's pot luck then at the end of the day") (e) the experience of having travelled in the third world (g) a resistance to reading into things (h) a philosophy of doing the same thing to every child and (i) wishing to avoid blame.

## **4.2 Control over birth events**

Birth is significant in the run up to vaccination because (for the first child at least) it is usually the first point in which parental choice becomes a major issue. It is also a key point at which parents balance choice and trust in a medical institutional setting, and experiences of their own autonomy in relation to medical authority. If health professionals are described as supportive by parents, this is an indication of the degree to which parents have experienced these relations in their favour. The extent of active choice, and the kind of birth that a mother chooses can also be regarded as a marker of the extent of her research and experience of dealing with often sceptical health professionals. While some mothers are already thinking about MMR around the time of birth while others' thinking begins later, and while there is obviously a time interval between birth and when MMR is due, our findings suggest some interesting connections between mother's engagement with birth and with vaccination.

There seem, for instance, to be possible links between giving birth in a midwife-led birthing centre with a strong emphasis on natural or active birth, such as the privately-run centre at Crowborough which a few mothers had attended, and later rejection of the MMR vaccine. It is possible that in such cases, both birth and MMR decision are shaped, at least to some extent, by a prior worldview emphasising a particular notion of "the natural". However, evidence from the narratives also suggests that birth experiences can actually shape and guide thinking about vaccination, whether by reinforcing or undermining a previously-held view. For example, and in contrast, for one woman the experience of a previous interventionist birth undermined her faith in the medical profession and reinforced her belief in "nature" and natural ways of doing things. In a somewhat similar vein another mother's experience of the interventions of premature delivery led to a heightened sense of the denial of her choice, and an increased sense that the MMR decision should be her choice.

Didn't have the choice of breastfeeding, she was so early she had to be droplet fed. Eye dropper thing because she didn't suck the bottle properly. So that choice was taken from her basically, didn't really want a Caesarean, wanted to just have gas and air, didn't want an epidural, heard horror stories, didn't really have the choice for that, that kind of choice was taken away from me. So in a way it made it easier?

(Young single mother)

Active research and interest in birth and in vaccination can also go together. Four mothers who invested a lot of time in their research and interest in birth and who started thinking about vaccination at least 4 months before birth went on to have single vaccines (relatively confidently) or not to vaccinate at all. It also appears from our narratives that informed rejection of the Vitamin K injection at birth is probably a good predictor of future concern with the MMR.

Birth experiences appear to be strongly linked to issues concerning parental (mother's) confidence, which as later sections will show has emerged from the narratives as a cross-cutting theme. Birth (whether in the framing of decisions, or in experience of control or otherwise over the process) is important to

building, testing or undermining confidence. The role of different kinds of antenatal class plays into this. The confidence required for a woman to negotiate the kind of birth that she wants may be much greater than that required to reject the MMR vaccination. It becomes pertinent to ask whether parents who have successfully achieved the birth they wanted gain a confidence and an increasing valuation of their own judgements that subsequently affects their interaction with health professionals and biomedical advice over vaccination.

### **4.3 Becoming a mother with other mothers**

*What information have you had apart from the newspapers?*

(Mother A) You probably get more information from talking like this, as a group, if (my friend) comes around we talk about different things, maybe I'll try that with (my daughter): you get more of an idea.

(Mother B) You feel that you can ask, you can't actually go to the doctor and say, look I've got a real big problem, life is really hard, I cannot cope, but you can say to your friends 'She's a nightmare, have you got anything I can try?'

(Mother A) Everyone's been through exactly the same. (Focus group in Whitehawk)

It is the rare mother who is not drawn into the way MMR is discussed along with other issues of concern (sleeping, feeding, behaviour) in the many groups most mothers participate in with their children. These range from HV or social services -run groups, to NCT and other voluntary parent and baby groups, to infant activity groups (e.g. music), to informal gatherings at mother's homes or in the park. In such situations any implicit hierarchy of knowing more than others, by virtue of having done more research or having older children, appears to be obviated by framing in an informal exchange of experience (implicitly contrasted with the more formal authoritarian engagement with GPs). This preserves the egalitarian and friendly ethos of such groups. The narratives, informal discussions and observations suggest that parents, by and large, do not seek or give advice but learn from hearing and sharing experiences and tips, in most cases valuing forms of information sharing that spring from the realisation of the unique relationship and responsibility that each mother and to a lesser extent father, has for their child. Our ethnographic work has not revealed anything resembling peer pressure to vaccinate or not to vaccinate; what does emerge is pressure to take seriously other parents' concerns, and a sense that to ignore concerns about MMR, one has to distinguish oneself as a mother from other mothers.

Mothers' need to pay attention to their children means that rarely are conversations long enough to discuss the issue at length, although mothers report that this often happens with close friends at adult social events. The ethnography suggests that the wish and need for a common camaraderie, affirming a new and growing identity as mother, is linked to a way of discussing MMR that emphasises suspicion of any denial of their right to choose. Evidence from mother's narratives suggests that however scientifically

informed a parent is, the powerful association between talking about MMR and fomenting relationship with other mothers means that failure to doubt and be suspicious of DH assurances that the MMR is completely safe, is to deny their newly established and valued relationships. Equally, strong identification as a mother means it is difficult not to relate sympathetically to the accounts of mothers who had their children vaccinated and then noticed a dramatic change in their behaviour. Mothers who have firmly decided either not to vaccinate or inversely who cannot understand parental concerns with the MMR, tend to be more inhibited in discussion around this topic and often do not express their opinions to the same degree as those who are more uncertain.

Through such mother and child groups parents are also exposed to a variety of other techniques and therapies (for example: cranial osteopathy, homeopathy, baby massage, baby signing) as well as other activity groups that may allow them to build confidence in embracing or rejecting alternative strategies for their child's health.

It would appear that such aspects of MMR talk are common to mothers living in both the Whitehawk and Fiveways areas. It may be, however, that experience differs between mothers of the older Whitehawk families, with strong community relations, and those of newly-settled mothers whose parenting relations are structured more through their engagement with health and social services. In this vein, four newly-settled single mothers expressed how in the absence of peer interaction, they felt isolated and vulnerable and how this overwhelmed their ability to make what they regarded as an informed choice for the DTP.

Had all of the baby jabs done. Because being on my own, as I said my mum wasn't down here and I hadn't established a group of friends down here, I felt really vulnerable. The responsibility of looking after him was extremely overwhelming.

(Single mother)

Here vulnerability is a marker of a lack of power (situation and confidence) and a reason for vaccination, or at least for handing over judgement about it to health professionals.

#### ***4.4 Engaging with health professionals***

GPs raise many concerns about the ways that parents interact with them over MMR. Some of these concerns echo the issues raised by GPs in wider fora (e.g. GP conferences); however others raise possibly more deep-seated reasons for MMR refusal which GPs realise shape their encounters, but which rarely surface explicitly, leaving them exasperated. For example:

I don't think I can be any more honest or open with them than I am at the moment given the information that I have, I haven't got any other tricks up my sleeve, to persuade them and as I said that's not my style anyway, but it does seem to be such a deep rooted 'No', the girls who are 18 coming in with their babies, they're not having their children vaccinated so it's straightaway.

GPs are also perplexed and interested to know more about the ways their discussions with patients fit into their ongoing processes of decision-making, and interactions with other sources of information. For example:

I really want to know [about] this mum who never came back. Why and where she got her information on MMR from, because it didn't seem to be from the mum. She'd read it or seen it somewhere, and just really didn't believe. And I don't understand that, and she wasn't keen on exploring it anyway, which is probably why she didn't come back. I was really trying to say that I am really interested to know why, because it is really interesting to know for other people not just for her. Why is it that they don't believe what the doctors believe, on the whole, and what the government are backing up?

As in these examples, it is the GPs' interests in the particular people and their experiences through which they seem to get at broader issues, and not their reading of surveys of parental attitudes. This contrast echoes that between the case-based ways that GPs tend to encounter illness, in contrast with the epidemiological framing of public health policy.

Most of the GPs we interviewed feel that they are not party to the decisions of most parents. Few mothers consult them and when they do, most have already made up their minds and are seeking support rather than advice. GPs' and HVs' encouragement of informed choice, at least in word, means that often their opinions are taken on par with those of other mothers. Health visitors for the most part appreciate the dilemmas parents are in, and do not by and large wish to compromise the relationships of trust they have built carefully over time. This makes them anxious to avoid anything that might be perceived as heavy handed advocacy to vaccinate. Their concern is for the overall health of the child and while this can be taken to include appropriate advice about immunisation, HVs are strongly aware that for them to have some say in this overall remit, they cannot afford to compromise a relationship that springs out of the issues that parents raise. In some cases their own experiences as parents give them an appreciation of the dilemmas parents are facing.

Moreover, vaccination may be a low priority for health professionals working with parents who are very deprived, with many related health and social problems. There are significant numbers of these in Whitehawk, even though they are not representative in the eyes of long term Whitehawk residents. As one GP described her work in Whitehawk contrasting it with other areas she had worked:

I think your role is much more, damage limitation, sometimes they have so many illnesses and so many risk factors, that you take the worst one and try to deal with that.

While an established relationship of trust may already exist or may be built with parents and health professionals through their mutual dealing with many childhood sicknesses and concerns this may not necessarily have implications for parents' vaccination decisions. Only in one dramatic intervention of a GP saving the life of a child with meningitis was a previous familial rejection of vaccination reversed, but

only for the mother and not the aunts of the sick child. What do parents mean when they ask GPs if they vaccinated their children? Might they on occasion, other than seeking confirmation, also implicitly be testing or challenging the wisdom of DH directives in the only way they know how, by suggesting that health professionals themselves might doubt that MMR is safe? Such a question could also be read as an attempt to engage with the doctor in a familiar way.

Many parents express that they do not raise their questions with GPs and HVs because of their perception of GPs' time constraints, their need to vaccinate for targets, that their advice will rarely be impartial and a sense of unequal power relations manifest in worry that they will be perceived as being ignorant.

Some parents are active in their engagement with health professionals. They know about the diversity of health professionals through their experiences and involvement with other parents. On occasion they will seek out particular doctors who will support their desire for single vaccines or their particular perspective on vaccination. Such an egalitarian engagement premised on common concerns or purpose is often highly valued, when it has been possible. For some, having a supportive health professional lends momentum to the process of research and of acquiring confidence in one's judgement. By contrast, other parents act passively. Some feel patronised or intimidated in engagement with health professionals, and this may partly explain seeming reticence to engage or an apparent lack of knowledge in biomedical terms.<sup>5</sup> This can be read, mistakenly, as passive acceptance (compliance) by health professionals. To quote one GP:

I think the majority of Whitehawk are not having to make those decisions, because they are allowing us to make those decisions, because they are quite happy to hand that over, that responsibility over, they don't want to have to think about that, hopefully because they trust what you are doing or don't have the space to put thought into it, I don't know.

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<sup>5</sup> The following explanation on this issue was given by a social worker with considerable experience in Whitehawk.

'I have to say in my experience women here are no different to anywhere else. They might be slightly less informed, some might be less, a little bit too scared to ask enough, once they feel they've been persuaded one way but I would say overall women care enough to know and ask the questions about their children if people will respond appropriately to them. If they feel dismissed they get angry and walk away. If they feel unheard or patronised it makes it very difficult for them to make an informed decision. So it's about the way people respond to them makes a difference to the choice they would make. Because most women who get distressed will walk away in anger and they can't make what I would consider to be an informed choice. They'll make some choice but it won't be as informed as they'd like it to be. I think that's so unfair, because if they get the right response then, with their hand on their heart, they can say they made the decision appropriately whereas this way when they make it in anger maybe they feel they did it too rashly.'



However, other GPs appear highly aware of how such institutional relations their encounters. For example:

She won't even come back and talk to me. She is not as educated, she finds it really threatening to talk about the details, and that [information] pack is very technical, which is one of the reasons that I wanted to see her again.

Parents registered with the Whitehawk clinic are less likely to have built up a longstanding relationship with their GP. Observation by social services may also make engagement with health professionals problematic because of a perception that they are being judged for their particular vaccination decision. Complete non-vaccinators share a frustration, nervousness and concern of being called to vaccination.

#### ***4.5 Parents' research and thinking about vaccination***

My friend asked me what she should do and I say whatever is right for you. I don't say, oh 'Don't do that', I'd tell them how I feel but 'you may have other reasons to feel how you feel' and she did have the MMR done. I didn't say 'oh you stupid' whatever, it was like 'Ok is the baby fine? Good'. You can't put your highly opinions on them, otherwise if they did what you did and they did catch something they could blame you, couldn't they?

(Mother of two girls/single vaccines)

The encouragement to research (or "to look into it" or "read into it") and then make up your own mind is a pervasive theme. Indeed in this respect the narratives suggest how vaccination has become a subset of expected personal research into parenting options and advice of all kinds, encompassing health, diet, sleep, behaviour and other issues. That parents are often implicitly defensive of not looking into vaccination in more detail, say they have postponed their research because of time constraints or argue against the need to research in the first place, is evidence of this.

Personal research is encouraged by other parents, and by GP's and HV's encouragement of choice. While people's engagement with information can always be regarded as active, as they come to it with previous knowledge that affects their interpretation, research can be defined as that process that goes beyond the exposure one gets by watching television, reading newspapers, browsing through magazines, or coming across information by chance.

Research, for those parents who take it seriously, becomes more a means than an end. Mother's narratives show how mothers start on a process that is rarely satisfactorily concluded by any vaccination choice, but rather accentuates a sense of doubt. It involves variations on and combinations of searching for recommended books, contacting parents' groups for advice, and surfing the internet. To become truly informed., mothers acknowledge, is a difficult process, which involves balancing the dramatic claims of individual mothers, the often overstated cases of anti-vaccination campaigners, serious work on history of

science and public health, and relatively inaccessible texts on immunology. It is thus not surprising that only those mothers who research to support a previously felt position end up taking a decision that they experience as relatively unproblematic.

#### **4.6 Wider trust in science and government**

*Have you been worried by any of the scandals about food that were reported in the papers?*

No, no (affirmatively), BSE! I was told that I was a mad cow anyway. It doesn't bother me.

(Mother: one child vaccinated with MMR)

In our interviews, more doctors than parents mentioned the controversies over BSE and over genetically-modified foods in the UK as an influence on parent's lack of trust. Very few parents, except some who did not vaccinate at all, volunteered the BSE "scandal" as a major factor in their decision or process of deciding about MMR. Is this because for the purposes of making a decision parents do not feel they need to have trust in the government, or in its handling of issues of science and technology more broadly? Trust, or lack of trust, in government appeared in the narratives as less relevant than mothers' personal confidence in their decision process. Thus, some parents' celebration of informed choice appears predicated on a form of personal responsibility that implicitly takes governmental fallibility into account. Very few parents mentioned recourse to blaming the government should vaccination go wrong, because of the parental pressure to research and make one's own informed opinion based on one's personal circumstances. In a sense a lack of trust in government (trust being manifest in passing decision for one's child health to governmental directives) is assumed by parents and thus not worth mentioning, unless one is making an altogether more courageous decision not to vaccinate at all (and thus distinguish oneself from most other parents). Within this parental rhetoric, parents have only got themselves to blame should their child become autistic because of the MMR vaccine. In this context GPs volunteering the fact of their children's vaccination becomes redundant, as some GPs recognise. For example:

*Do your patients ask you whether you had your children vaccinated?*

They sometimes do and if they don't I quite often say.

*Do you find that's more convincing?*

Well I hope so, but you think of the John Gummer beefburger incident, that didn't exactly reassure the public (laughter), so I don't push it down their throats. He was prepared to sacrifice his child. I think most people find it reassuring that I feel that it's the right thing for my children as well.

The acceptance of personal responsibility is already manifest in the frequent statement 'I couldn't forgive myself if [my child became autistic; my child developed complications from measles]' explaining both non-vaccination and vaccination. People's particularity of responsibility for children is already, in some senses, a reflection of an established lack of trust. Might there be a correlation between a lack of that

intense responsibility for one's child and trust in DH or professional directives? Some parents certainly seem to be less anxious and express less responsibility for their children while attributing public institutions with greater knowledge and right to intervene.

#### ***4.7 Understandings of vaccination and contra-indications***

Pareek and Pattinson describe how in their survey 27.7 per cent of respondents cited 'invalid contraindications' to MMR vaccination, giving the example of 'adverse reactions to previous vaccines for family members' (2000: 970). However, our narratives reveal a variety of ways in which parents conceptualise possible vaccine contraindications that are logical to them within the framings of their personal histories and experiences. Many parents hold to the idea that three vaccines are too many for the immune system to cope with and can "knock back" a child. Others invoke ideas that can be broadly summarised as: (1) increased susceptibility reflected by the presence of some disorder within the child or family, (2) the value of natural immunity and supporting it with nutrition, and (3) the particularity of individual immunity that links on occasion to hereditary factors.

Some mothers cite conditions such as eczema, asthma, allergies and learning disorders of parent or child as making a child more likely to suffer serious effects from the MMR vaccine. They find affirmation for such views in the advice of certain doctors and those who run single vaccine clinics – although it could be argued that the latter have (commercial) interests in picking up on and promoting such views. This field of reflection and discussion leads some parents to regard the MMR as appropriate for most people, but not for their own child because of a particular weakness or susceptibility. Not knowing about this particular weakness may be reason enough to avoid the MMR. Here not knowing the risk, but the possibility of risk – in other words, uncertainty – is sufficient to reject vaccination.

Some mothers describe the possible effects of measles infection on their child in similarly particularistic terms. How vulnerable their child might be to serious side effects from measles depends, in this view, on the strength of their immunity as acquired through nutrition and appropriate nurturing. In some cases, mothers back up such thinking with the idea of valued acquired natural immunity or by a historical or geographic appreciation of the association between measles morbidity and nutrition.

It is not entirely clear how far parental engagement with the ideas of homeopathy explains the wide variety of contraindications to the MMR vaccines and reasons to postpone that many parents cite. Although there are several homeopaths in the Brighton and Hove area who strongly critique vaccination, and although there are correlates in homeopathic theory to most of the parents' ideas about contraindications cited above, not all parents who use homeopathy refuse to vaccinate nor do all non-vaccinators embrace homeopathy or homeopathic ideas. Several parents suggest, however, that more experience of alternative remedies would be more likely to lead to rejection of the MMR.

The particularity of each child is experienced through their different personalities (implicitly or explicitly compared to other children) and the history of their weaknesses and strengths, and conceptualised through a sense of the particularity of each person's immune system. Parents' link to and responsibility for their child is in a sense affirmed through ideas (attributed to homeopathy or not) that

may see parental illness susceptibilities passed on to their children. Even the TB of a child's grandparents may be conceptualised as manifest in their constitution. The idea of particularity is another reason why some mothers would see their particular decision as not being relevant to other parents.

#### **4.8 Final action?**

I don't feel we have enough information. I sway one way then the other. Single vaccinations concern me too. Confusion really. When I do do it, and I probably will, it will be closing my eyes, running and jumping.

(Mother of three-month-old baby)

The widespread concern with the MMR, and that seemingly few people among the people we interviewed vaccinated or intend to vaccinate from a position of confidence, are manifest is the wide range of decisions that parents take. Parents participate in the agonising of other parents, they hear the stories of "vaccine damaged" children, they prevaricate, they talk conspiracy, they believe many of the DH list of myths but most still go on to vaccinate. Why? In parents' theorising about other parents' final decision in relation to their own, it was often the fact of lack of confidence or lack of knowledge that explained their decision to vaccinate. Confidence and knowledge were somehow equated and took precedence over what might be regarded as scientific proof.

I'd have to be a lot more knowledgeable not to have it.

(Mother of 6-month year old child/unsure about MMR)

I'm not confident enough to go down the non-vaccination route.

(Mother of 6-month year old child/ intends to have single vaccines)

This was also evident in one of the most common statements of both parents who vaccinated and who did not vaccinate, but did so acknowledging their lack of knowledge. This affirms Evans *et al.*'s finding that parents in Bristol who immunised did so because of compliance rather than out of an informed positive choice (Evans *et al.* 2001). 'I couldn't forgive myself if she got measles (or autism)', seems to explain a final decision taken out of lack of confidence, anxiety, lack of knowledge and an exaggerated sense of responsibility. The importance of avoiding blame, which may be felt more acutely by single mothers, along with lack of confidence ties into a heightened experience of vulnerability that many single mothers explained as motivating their final decision. Other parents have a gut feeling or vague sense that something needs to be done, a disposition that can be seen to originate in the structural relations between health institutions and publics. Parents may vaccinate out of a sense of respect for the professionalism of a family member who succeeded as a health professional. Implied in a wish not to research or to do what one is told is an acceptance of the relationship status quo between the individual and professionals.

Those who mention contraindications in their narratives often do vaccinate after a period of postponing once they can see that their child's constitution is strong enough, or that the child has passed through a period in which they are perceived to be more susceptible to contraindications. A greater susceptibility to measles may also be the final impetus to mothers who are undecided. A reported measles outbreak in the area – though subsequently not confirmed by testing – was sufficient for some mothers to go and seek vaccination.

Even amongst parents with longstanding, research-based, informed concerns in favour of vaccination, the final decision to vaccinate may be postponed for logistical or familial reasons. Several mothers only consented to vaccination once their husband finally agreed to take the children, claiming that they could not bear to see their children suffer. However, they were perhaps implying the need for combined parental responsibility on the issue, affirmed by the fathers or other family members actually taking the children for the deed.

Thus the final decision to vaccinate does not necessarily reflect resolution or acceptance of the safety of the vaccine. It may on occasion be a simple realisation of not being able to afford single vaccines. The narratives suggest that one can still vaccinate voicing both exaggerated risk of the side effects of autism and serious dangers of measles infection. It may also be a spontaneous or professionally encouraged decision done on the spur of the moment, when in the surgery for other business.

The difficulty in deciding and dealing with the wide variety of economic factors, class influences, pressures, and implications for her parenting are captured well in the narrative of a 21 year old single mother from Whitehawk who has postponed the MMR vaccination for about six months.

*Do you ever get to the point when you can decide?*

She's going to have it, I've been told, her dad's told me he wants her to have it, and it's a strong thing that he wants her to have it, so he's going to take her to have it, and I'm ok with that, I don't want to take her to have it, really.

*Do you feel because it's his decision because he took the responsibility, takes the pressure of you a bit?*

A bit yeah, I do feel like it's a lot of pressure, and I do think she should have it, really, realistically. I just cannot pay for single ones. If I could afford it, I would have single ones. Maybe that sounds really strange to some people but there's no other way, which I think is a really bad idea, why should your child's development maybe suffer, we don't know yet, because you can't afford it, because you have money you have the right not to be ill. That's not really fair is it, that's why people in our background are never going to get out from where we are, because we can't afford it, we can't afford to do that.

*How come your partner is so sure that it's right?*

Well, . . . hmm. She needs to have something done. I'm weighing up the pros and the cons of it, for her to have it, she could become autistic then that's the chance you are going to take. If she doesn't have it, she could get very ill, she could die. Then realistically I'd rather she be autistic. It sounds

really silly, maybe, I'd rather take that option, if she's still here with us, and I would still love her, she is still my child, rather than thinking to myself I'm putting her through all that illness, for nothing, you know, when really I could vaccinate against that. It's probably less chance of her becoming autistic than there is of her actually getting ill. Even if she didn't get really poorly she'd still get ill, she'd still get it, she's having it now, (laughing . . .) I'm not quite sure but she's having it.

While a choice must be made the process of learning about MMR continues and plays a role in future vaccination decisions for future children. Having the MMR, in this respect, is more final than non-vaccination or single vaccination which requires a continued engagement to affirm the position taken. Yet many parents remain undecided about the science, continue to learn and say they remain open despite having taken a decision that is irreversible.

You've got to hope and pray that the decision that you made was the right decision, yours and your own.

(Mother, one child vaccinated)

In the immediate weeks after vaccination, parents may be aware of possible side effects and express relief that nothing serious happened. A final decision does not necessarily make them more for or against vaccination. And future children may not be vaccinated with the MMR even if previous children were. Some parents, because they perceive all their children to be susceptible to conditions inherited through both parents and given confidence through the experience of having single vaccines, may then routinely single vaccinate following children with little further research. One parent postponed the decision until she felt her children could decide for themselves. Mothers who do not vaccinate at all have to be circumspect in communicating their decision to health professionals and may claim to be postponing the decision not to risk censure.

In remembering and communicating their decision to other parents in various stages of the process and in the somewhat restrictive social environments in which they communicate, some issues, such as the importance of choice may hold sway over the difficult verbalisation of other more ambiguous experiences.

*Do you think you think about it differently now post event than the way you were thinking about it then?*

Possibly, I think, I don't think I would change my mind and have the MMR but I don't necessarily think the MMR is a bad vaccine, that there is a problem with the vaccine I just think there should be a choice for parent to, you know so that you can make the decision yourself. Unless something comes out that there is absolutely no link with autism, it is completely safe I think the choice element should be there, and that's how I felt at the time that I wanted to make that choice and that's what I chose for my children. But I just think the choice should be there for all parents. You know we were lucky that one of the vaccines we didn't have to pay more and the others we could afford to pay for.

(Nurse and mother of two children both vaccinated with single vaccines)

## 5 Conclusions – reframing the debate?

The ethnographic and biographical approach taken in this first phase of our research has reframed parents' perspectives on and practices in relation to MMR in two main ways. First, it has demonstrated and illustrated the influence of wider social issues and contexts. Second, it has shown how MMR practices are part of an unfolding of parents' experiences in relation to child health and the institutions they encounter through this, and are shaped by other aspects of these experiences.

The survey phase of the study is designed to probe these themes for their significance. It will see whether issues that have emerged from the limited number of detailed cases that we have been able to examine during the ethnographic work are significant in relation to issues such as MMR uptake, timing, delay, choice of single jabs, uptake of other immunisations, and so on. It is also designed to ascertain how, and to what extent these influences themselves vary across the social make-up that is Brighton and Hove.

While it is too early to draw strong conclusions from this research, the themes raised in the ethnographic work so far do raise some pertinent questions that are not currently central to policy and public debates around MMR, yet are perhaps worthy of greater attention. In these interim conclusions, then, we highlight some of these themes, the challenges they raise, and ways in which they might begin to help reframe debate in productive ways.

### 5.1 Particularity and choice

#### 5.1.1 Parents' conceptualisations, and public health agendas

A strong emergent theme in the narratives is parents' tendency to conceptualise their child's health, and immune system, as highly particular: shaped by a specific path of events extending back into family health history, birth, illnesses and other events, and incorporating concerns about sleep, allergies, eczema, asthma, dietary tolerances, character and behaviour. This extends into ideas about a child's particular vulnerabilities – to the effects of measles, or of vaccination. It is largely in these terms that parents reflect on MMR “risks” or “safety”: not in general, but “for my child”.<sup>6</sup>

This sense of pathways of vulnerability (or invulnerability) in turn shapes a concern, amongst some, for a more personalised vaccination trajectory, as regards which vaccines, how they are timed, and so on, tailoring vaccination programming to particular vulnerabilities. This raises important questions and challenges for policy, where uniform vaccination programming is the norm both because vaccination is a public health area, implicating the social good, issues of herd immunity and so on, and for reasons of health service efficiency. Many of the parents' narratives that we have heard implicitly suggest a desire for greater flexibility in immunisation policy, to accommodate individuated priorities, raising real policy dilemmas.

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<sup>6</sup> Martin (1994) argues that immunological cultural metaphors pave the way for new forms of social hierarchy, in the privilege of more “flexible bodies” or the means to attain them. While her flexible bodies are a positive attribute, our mother's accounts within immune system thinking rather emphasise “vulnerabilities” – a more negative attribute, but also a differentiator.

Perceived vulnerabilities, and particularistic health trajectories, also underlie, at least for some, the desire for “choice” of single vaccines to be freely available; bringing an important but hitherto underplayed perspective to an issue which has come to dominate media and policy debate. For as public debate on MMR has proceeded, amongst health policy-makers, professionals, pressure groups or in the media, it has come to turn increasingly on the issue of choice, and in particular on choice in relation to the question of single vaccines. This has brought out an apparent contrast between the DH’s “denial of choice” in not making single vaccines available, and the DH’s and government’s framing much of its relations with the public over other issues in relation to “patient choice” and active citizenship. Thus current National Health Service (NHS) initiatives advocate the active partnership of health professionals and patients (NHS Executive 1996) and the encouragement of patients to choose between options through the improvement of information (NHS Executive 1995; Ford *et al.* 2003: 590). Choice is also a centrally advocated principle of GPs’ and HVs’ engagement with publics, affirmed most recently by Dr Bogle in a recent BMA report backing “non-compulsory” triple MMR vaccine: “The doctor-patient relationship is based on trust, choice and openness and we think introducing compulsory vaccination may be harmful to this.”<sup>7</sup> Specialised single vaccine clinics and doctors offering the single vaccines, champion parental choice and thus avoid direct confrontation with the DH on the more contentious issues of possible side effects of the vaccine. The DH and other public health officials reasonably counter that an individual-choice ethic is inappropriate for vaccination because as a public health issue, individual decisions have implications for other children. Yet these mothers’ narratives from Brighton highlight possible challenges to the instilling of such a public health ethic around vaccination, beyond the “selfishness” that some popular commentary assumes: more significantly, it would appear to run counter to basic concepts – of particularistic immunity, and individualised vulnerabilities – that guide how parents are thinking about their children’s health and vaccination. The narratives also indicate how wider societal trends (for example: older parentage, increased experience of choice at birth, wider access to parent support groups, increased access to information, rising incidence and concern of asthma and eczema) underlie parents’ desire for choice, and their confidence to pursue it.

### ***5.1.2 The importance of personal and social circumstances***

Furthermore, the current casting of debate about choice focuses attention on MMR as a single decision, and on the proximate factors influencing it. Our research so far indicates that this may misconceive the process through which people come to engage with MMR. Actual outcomes may be better understood not as a response to singular deliberation and the information that informs it, but as heavily dependent on particular combinations of personal and social circumstances in an evolving engagement with the issue. This may not stop with immunisation (or without it). Seen in this way, seeming compliance on the part of parents may not reflect their actual concerns or any realisation that MMR is “safe”. Equally, people do not necessarily vaccinate because they understand vaccination better.

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<sup>7</sup> 30 June 2003, ‘BMA backs “non-compulsory” triple MMR vaccine’.



### **5.1.3 The role of information**

The current policy debate on influences on MMR practice is dominated by a particular view of informed choice and the role of education in influencing decisions. Yet as our research indicates, this obscures questions concerning the place of information amidst the personal and social processes that shape MMR practice, and how trust in different sources of information is embedded in the social relationships that people have with their providers. Parents by and large particularise the value of science as it applies to their own situation and history and cannot help but be guided by their own knowledge and experience. Some are critical of the “textbookishness” of health professionals who just repeat what they see as “DH wisdom”, not informed by experience. The narratives of these Brighton mothers would underline the limits of any strategy for interacting with parents based on information and education alone. This both overplays the importance of information itself in parents’ perspectives on immunisation, and risks overlooking broader social processes and issues.

### **5.1.4 Obscuring scientific debates**

The current focus of public debate on choice has served to deflect attention from the scientific content of the debate over MMR and from the current structures of scientific and policy practice which lead to parental “alienation” and which are at the root of parental distrust. In short, with increasing focus on “choice” between alternatives, key issues rooted in public engagement with the science have been obscured. The narratives show how parents perspectives are grounded not in myths or ignorance that can be vanquished by education, but in a range of forms of “experiential” knowledge which lead them, for instance, to relate possible vaccine effects to their individual children’s births, feeding and sleeping patterns, allergies, and other vulnerabilities, and to family histories which they see as influencing these. In some cases parental interest in such issues is supported by their engagement with complementary practitioners such as homeopaths. When vaccination becomes a dilemma, parental deliberation over it feeds into these issues.

Many studies and much educational literature have tended to devalue and write off such reasoning and concerns as rooted in misinformation, and misconceptions concerning vaccine contra-indications. Yet if such perspectives are driving parents’ concerns and shaping the ways in which they read other information that they come across, then they need to be taken more seriously, and attention needs equally to be paid to strands of scientific work which might prove to support them. This underlies parental calls for improved dialogue (not simply information) over these issues (see also Evans *et al.* 2001). It also underlies parental calls – articulated in particular by advocacy groups such as *Jabs* – for new research (and transparency of conduct in research) on questions that would interest parents in informing such dialogue. Notably, the questions raised by parental groups often appear driven by a concern with the particular vulnerabilities of individual children which echoes that in Brighton mothers’ narratives.

The increasingly entrenched, politicised and polarised terms in which the MMR is currently being discussed in the media leaves little space to consider such research or dialogue, and thus moves away from common ground or room for discussion between scientific experts, those who transmit their knowledge and parents.

#### *5.1.5 Wider social trends*

It is important to consider whether and to what extent some of the themes raised in these Brighton mothers' narratives are new. If they are, then this might indicate that the current evolution of the MMR vaccine "crisis", and of possible crises which may arise in the future, cannot be expected to mirror past experiences (such as over Pertussis).<sup>8</sup> In particular, it is plausible that current parental conceptualisations of their child's *particular* health trajectory, immune system, and response to vaccination have become accentuated over the last decade or more, encouraged by a widespread and popular appreciation of the new genetics of disease, as well as of the personalisation of immunity (Martin 1994). Equally, it is plausible that a new equation has come to be drawn (in some circles at least) between the good parent and the parent who, as the best expert on their own child, seeks to negotiate the wide variety of advice on parenting with the child's individual particularities. Such a parent also expects their peers to do the same, accounting for the respect in these narratives apparent for other's different decisions over vaccination. This can be contrasted with an earlier acceptance of more authoritative and generalised routines and regimes of child care; a transformation visible (but by no means total) in, for example, the tenor of child care advice books from the 1970s (e.g. Spock 1976) to the present (e.g. P. Leach 2003).

Personalisation of ideas of vulnerability and risk, and responsibility to deal with these – so evident in these narratives – would according to Beck (1992) and others be a manifestation of a contemporary "risk society" in which people are aware of the inability of public institutions to deal with the hazards thrown up by modern technology – as manifested through wide public examples such as BSE and controversies over GMO. If these are true transformations then the current evolution of the MMR vaccine "crisis", and of possible vaccine crises which may arise in the future, cannot be expected to mirror past experiences and simply fade away; but is qualitatively different, unfolding as part of, and an exemplar of, changing cultural paradigms and science-society relations.

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<sup>8</sup> In this vein, it would cast doubt on predictions of the following kind: 'The situation should improve soon, predicts vaccine safety expert Neal Halsey of the Johns Hopkins School of Public Health in Baltimore, Maryland. "Overwhelming" evidence that MMR does not cause autism combined with continued measles outbreaks, will slowly turn public opinion he says. "It just takes three to four years for new evidence to sink in."' ([www.nature.com/nsu/030804/030804-12.html](http://www.nature.com/nsu/030804/030804-12.html)).

## **5.2 Parental confidence and engagement with institutions**

### **5.2.1 The role of health professionals**

The reframing of MMR practices that our narratives indicate, displacing the focus from the idea of “decision” and “information” to wider social processes and relationships, also has implications for how relationships between parents and “frontline” health professionals are understood. Our narratives and interviews with health workers help to contextualise their influence, suggesting that health professionals’ advice alone is rarely key. Rather, the extent to which they shape parents’ practices depends very much on when, in a parent’s process of thinking and amidst a range of other social interactions, these encounters take place.

Moreover GPs and HVs are people too. As (with) parents, health professionals’ perspectives are informed by a multiplicity of and conjunction of influences in which personal, philosophical, political agendas and previous engagement with health services feature to varying degrees. Most of the HVs we interviewed feel that their primary accountability is to parents and to forging and maintaining a supportive relationship with them. In this context they may make available diverse sources of information about vaccination, not just those supporting the DH position. Key to successful health visitor engagement with parents is their appreciation of valued ways of relating and of talking about information. Many feel that expressing their personal views is a constrained and difficult issue, however. This is illustrated (in the extreme) in a recent article based on sources from Direct Health 2000, which suggested that ‘almost half of parents opting to give their children single vaccine alternatives to the controversial MMR jab work in the health service’.<sup>9</sup> It quoted a dissatisfied GP, who they purported ‘felt extremely guilty about bringing his son to us on a Saturday for the SepVax course, when he had been advising patients to choose the combined MMR jab all week.’

### **5.2.2 Parents’ relationships with institutions**

At the same time, the narratives begin to suggest how broader social and institutional relations shape people’s interactions with health professionals. Some mothers do not ask questions of GPs and HVs not because they have no concerns, but because they do not feel empowered to raise them with those they perceive as in authority. The powerful assumption that vaccination is necessary means that some parents feel an obligation to vaccinate, and worry they will be judged as a bad parent for not doing so – with possible repercussions in adverse interest from social services. Implied irresponsibility and bad parenting may dominate over any discussion of the issue that compares the merits of each possible vaccination

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<sup>9</sup> ‘Health workers reject triple jab’, 1 May 2003, Madeleine Brindley, Health Editor. Madeleine.Brindley@Wme.Co.Uk, *The Western Mail – The National Newspaper Of Wales*. ‘Research by Direct Health 2000, which runs satellite single-jab clinics in Swansea every three months, showed almost 50 per cent of parents attending its sessions were health professionals, compared to 40 per cent elsewhere in the UK. Of 1,042 children who received separate measles, mumps and rubella jabs at a session in Swansea, the heart-land of the anti-MMR campaign in Wales, 493 (47.3 per cent) had parents who work in healthcare occupations.’

choice. The question ‘Don’t you want the best for your child?’ can carry quite threatening overtones to those who feel vulnerable or disempowered in the face of authority, or for whom being judged a bad parent could have serious material and social consequences.

### *5.2.3 Parental confidence*

Information is frequently given by professionals with the expectation that parents will vaccinate. Going against such expectation requires the individual to make a stand, and to become confident. The narratives indicate many ways that this can happen. It may be through accessing alternative knowledge, through people’s own research into the issue, or through their engagements with other parents. Indeed, the increasingly accessible printed and online literature; parents groups, and the loose social movement of concerned parents (e.g. *Jabs*, *The Informed Parent*) all help to give parents confidence in adopting perspectives and practices that contradict professional recommendation. The ways in which parents communicate their reflections to each other appear to affirm a common cause in the face of uncertainty that similarly reinforces parental confidence to go against professional expectation. Parents’ styles of talk over MMR also seem to promote trust in the accounts of parents who claim their children to have been detrimentally affected by vaccines. In effect, not to take these accounts seriously is to deny the value one puts on one’s interactions and knowledge-sharing as a parent with other parents.

The recommendations of health professionals, or DH immunisation information, may be “read” or reacted to quite differently depending on where people are in such processes of confidence building when they encounter them. The narratives of these Brighton parents illustrate a spectrum from less to more confident. They indicate how confidence shapes engagements with health professionals over the MMR issue, and how confidence can in turn be further boosted or undermined through these engagements. Appreciating these dynamics could further help to reframe the place of immunisation information in people’s practices around MMR. It would also locate it as a contributory element in the structures of authority within which people’s reflections and actions are embedded.

Health policy-makers tend to be shielded from the often uncomfortable ambiguity, diversity, and individuality of particular parents’ histories and their engagements with the issue of vaccination. This is in part the result of research practices that downplay the validity and individuality of motivation and action, and that present information in an over-generalised form. It might assist mutual comprehension if health policy-makers were to engage with the rawness of particular parents’ histories, and to relate to individuals who have taken “informed” decisions that government vaccination policy-makers would regard as completely foolhardy. Such a modality of presentation of parents’ histories and processes of coming to knowledge about vaccination as we have attempted in this paper thus has policy implications in itself, perhaps serving to reveal more vividly to health professionals the diverse perspectives and ongoing dilemmas of the parents with whom they interact.

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